



**FASD**

FASD SUPPORT NETWORK  
OF SASKATCHEWAN INC.

SPRING 2010

# LIVING WITH FASD

*Feature Articles to Encourage  
Hope and Inspiration*



[www.skfasnetwork.com](http://www.skfasnetwork.com)



## Network Board Members

*The FASD Support Network of Saskatchewan is a parent-led provincial organization. We have an active and hardworking volunteer board of directors who are deeply passionate about the many issues associated with FASD.*

While it really does take a high level of passion and commitment to be a member of a board of directors, there are also a number of benefits. One benefit, particularly important to our organization, is the opportunity for parents of children, youth or adults living with FASD to participate on the board as a way to connect with others who understand their experience. Participation on the board also creates opportunity to have a voice and influence important issues. Whether a parent or not, the shared commitment and sense of accomplishment gained by working toward a common goal is a vital benefit of board participation. If interested in joining the Network board, please contact Trudy Shingoose, president of the board, at [tshingoose@sasktel.net](mailto:tshingoose@sasktel.net) or call the Network office for more information.



Pictured left to right: Rae Mitten, Shirley Hellquist, Tracy Breher, Sandy Overs, Sylvia Nagy, Tracey Neudorf, Lisa Brownstone, Trudy Shingoose Sharon Taylor. Not in picture: Kim Skidmore and Marilyn Macdonald.

## Network Staff



**Lynette Janzen**  
Events Coordinator



**Beverly Palibroda**  
Communications Coordinator



**Jessica Kaban**  
Executive Director



### Living with FASD

Spring 2010  
Writer/Editor: Beverly Palibroda

*Living with FASD* is published twice yearly by the FASD Support Network of Saskatchewan Inc. This publication is a benefit of a \$15.00 membership available by contacting the office.

### Article Submission

Plans are underway for the next issue of *Living with FASD*. We welcome personal stories, poetry, photos, article reviews or research findings. To discuss submissions please contact the Network at (306)975-0806 or E-mail [fasdcommunications@sasktel.net](mailto:fasdcommunications@sasktel.net).

Deadline for submissions is August 1, 2010.

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### Network Website

Just a quick reminder to stop by the Network website for your informational needs. We are just a few mouse clicks away.  
[www.skfasnetwork.ca](http://www.skfasnetwork.ca)





## President's Message

by Trudy Shingoose

*Here we are in a brand new decade! This will be the decade of hope for positive and healthy supports for those with an FASD and their families.*

This is the decade that governments, schools, and other professionals will fully appreciate the complexities of FASD. The

FASD Support Network of Saskatchewan will continue to educate people and organizations so the level of expertise around FASD will continue to rise. As an organization we will be there to further advocate for the resources and supports individuals with an FASD require throughout their lives. Together we will continue spreading the importance of having an ongoing individual life plan for each person with an FASD so they can recognize themselves as safe, supported, valued and contributing members of the community.

This will be a decade for putting worldwide knowledge about living with FASD into action. Program development for support needs to be pulled off the shelves and implemented in areas of education, work experience, parenting, and housing. Our communities will be knowledgeable and strength based, focusing on positive and healthy outcomes.

FASD will finally be recognized as separate and unique as the individual. Stigma will be replaced with understanding and acceptance.

This will also be the decade that individuals, families and professionals will speak as one voice. Local, provincial, national and world governments will begin to hear this voice. This voice will get louder and clearer until the levels of government finally hear the message. The days of myths, misconceptions and ignorance will no longer be excusable. Start off this decade by joining this voice, write to your Member of Legislature, the Premier, member of Parliament and the Prime Minister. If you are a parent or family member share your story. If you are a professional write about the lack of resources and supports for your clients. Speak out about the success individuals have experienced with support and also the trauma experienced when needed supports are unavailable. Share your vision of what should be accomplished this decade in the area of FASD.

To continue moving forward, the Network relies on the strength of our staff and board members. We are presently looking to fill a few vacancies on our Board of Directors at the Annual General Meeting in June of 2010. Our Network board is a volunteer parent

based group who come from various parts of the province. Our term is two years which can be renewed if you wish to continue on the Board. We are looking for individuals who have the time to commit to at least six face to face meetings or functions a year as well as various teleconference calls. We welcome interest from all areas of the province. If you are interested in becoming a part of "the voice", or know of anyone that would be, please contact the network for more information.

## Contact Us

### **FASD Support Network of Saskatchewan**

510 Cynthia Street  
Saskatoon, SK S7L 7K7  
Toll Free: 1-866-673-3276  
[www.skfasnetwork.ca](http://www.skfasnetwork.ca)

#### **Jessica Kaban**

Executive Director  
(306) 975-0884  
[fasdnetwork@sasktel.net](mailto:fasdnetwork@sasktel.net)

#### **Beverly Palibroda**

Communications Coordinator  
(306) 975-0806  
[fasdcommunications@sasktel.net](mailto:fasdcommunications@sasktel.net)

#### **Lynette Janzen**

Events Coordinator  
(306) 975-0896  
[fasdoffice@sasktel.net](mailto:fasdoffice@sasktel.net)

The days  
of myths,  
misconceptions,  
and ignorance will  
no longer be  
excusable.

# Around the Network Office

Over the past several months the Network has hosted a number of exciting community workshops and training opportunities funded through the Ministry of Health's Cognitive Disability Strategy and the Saskatchewan Liquor and Gaming Authority. It's been great to see so many community members interested in learning more about FASD. Here are a few highlights of our events:

We

hold many events each year. To find out about upcoming events, contact us and ask to be added to our Email list.

## **FASD: Discovering, Connecting and Creating Change**

In September 2009, 250 participants attended a two-day conference planned by the Network and the Saskatchewan Prevention Institute. One of the highlights of the conference was a celebration banquet honouring individuals living with FASD, their families and the professionals from all sectors who offer support.

## **Saskatchewan FASD Speaker's Bureau Retreat**

In October 2009, members of the Saskatchewan FASD Speakers' Bureau met in Waskesiu for two days of training. Bureau members continue to enhance their skills and gain valuable information to take back to their home communities. Call the Network to learn more about the FASD Speakers' Bureau.

## **Parent Retreat 2009: Living with Hope**

Our third annual Parent Retreat was held in November. Parents and caregivers of children, youth and adults have

come to look forward to this rare opportunity for a time of uninterrupted refreshment and relaxation. Parents had time to learn and time to enjoy the company of others who understand the unique challenges of parenting individuals living with FASD. Participants laughed, listened, shared stories, built friendships and even sang along with presenter, Wendy Edey. Wendy encouraged the parents to find hope through the ups and downs of daily life. Participants also had time to enjoy a bit of pampering that included massage therapy, manicures and reflexology. Overnight accommodation and meals were provided, and each participant received a gift bag with resources about FASD and living with hope.

## **Mental Health and FASD: Psychotherapy, Supportive Counselling and Treatment Approaches**

In recent years there has been a growing awareness and more questions about the links between mental health and FASD. This workshop was designed to help mental health professionals meet the complex mental health needs of individuals and families living with FASD. Brenda Knight, a registered psychologist with ample expertise, talked about the challenges that can affect the emotional health and behaviours of someone with FASD. She provided many examples from her experience and offered techniques that counselors and therapists could apply in their clinical practice.

## **Practical Approaches to Challenging Behaviors in FASD**

Callers to the Network commonly request direction on practical strategies that they can use in their daily lives. In February 2010, 400 people had the opportunity to gain information from presenter, Nathan Ory. The workshops were designed to provide effective strategies for supporting individuals with FASD, particularly when challenging behaviors are present. Participants at each location, Saskatoon and North Battleford, received Nathan Ory's book, *Working with People with Challenging Behaviors: A Guide for Maintaining Positive Relationships*. This book, along with two days of training, has undoubtedly given many parents and professionals a host of practical tools.

## **Lunch and Learn about FASD: How to Provide Effective Support**

In March 2010, professionals who offer direct support to individuals and families living with FASD were invited to attend lunch time presentations in two locations: Yorkton and Prince Albert.

A Lunch and Learn event is a one way to introduce the topic of FASD to folks less familiar with this topic. The informal atmosphere is also ideal for connecting and networking with others in the community. These events, with a focus on effective support strategies, were well attended and appreciated.

# Information and Resources

## **Book Review: So You Have Been Diagnosed With FASD Now What? — A handbook of hopeful strategies for youth and young adults**

### **Review by Beverly Palibroda**

*I am always on the hunt for new information and resources about FASD. I feel fortunate when I discover genuine treasures. This booklet, written for youth who have been*

*diagnosed within the spectrum of FASD, is indeed a treasure.*

*Published by the Boyle Street Education Centre in Edmonton, Alberta, the goal of this handbook is to help young people, learn more about Fetal Alcohol Spectrum Disorder (FASD).*

There is a known need for information written specifically for youth and adults

affected by prenatal alcohol exposure. This booklet helps to fill that gap. I can see this booklet being a valuable tool during conversations about FASD, with youth and adults. The hopeful tone and careful choice of words used to convey the messages throughout will be beneficial in helping youth and adults understand their disability in a realistic and non shaming kind of way.

The author models this word choice and offers up the words and language youth can use in their daily life to talk about their own experiences.

I also see merit in the blend of information and practical strategies suggested. The strategies are an important step in helping to empower youth to implement the approaches and ideas that work for them.

A key message early on in the booklet is that each person is different and that each reader can choose which ideas and strategies will work for him or her. The inclusion of several short activities and quizzes, designed to help each youth better understand her particular strengths and struggles, means that she is not simply using every strategy but is actively participating in selecting approaches while learning about herself. Because the quizzes can be completed right in the booklet, the knowledge or insight can be revisited regularly and the youth can feel some ownership over the

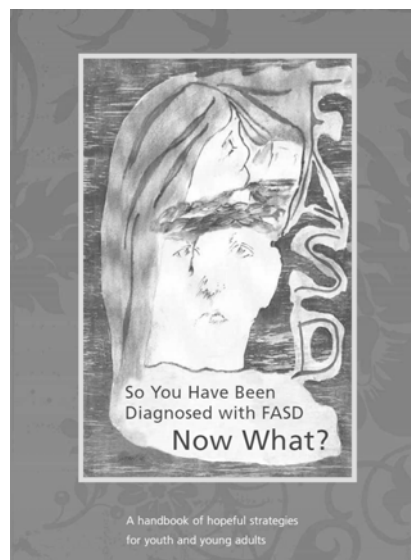
gathering of this information.

This is an ambitious booklet and the author tackles several key issues like:

- ... understanding different learning styles,
- ... developing relationships,
- ... understanding sexuality,
- ... managing feelings,
- ... doing better in school,
- ... learning life skills,
- ... dealing with police
- ... learning about alcohol

I appreciate so many things about this booklet, from the language used, the positive tone, the key issues addressed, the use of practical strategies, to the small and portable size. I encourage you to take a look at this booklet. It is readily available online as a PDF document or can be ordered for \$5.00.

The hopeful tone and careful choice of words used to convey the messages throughout will be beneficial...



## How to Order

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Boyle Street Education Centre  
and Agnieszka Olszewska

A free PDF version is available  
from [www.bsec.ab.ca/](http://www.bsec.ab.ca/)

Print copies available for  
purchase for \$5.00 from :  
Learning Resources Centre  
12360-142 Street NW  
Edmonton, AB  
T5L 4X9  
780-427-2767

# Community News and Activities

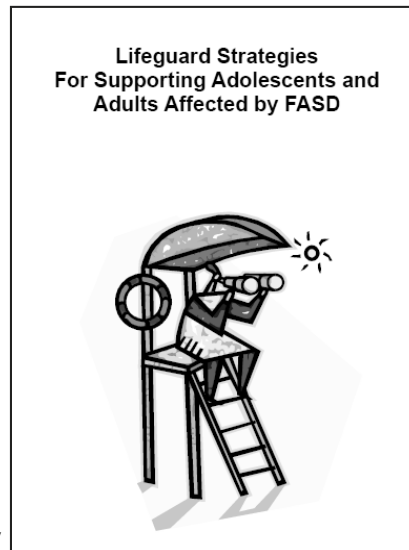
## **Reprint of Lifeguard Strategies for Supporting Adolescents and Adults Affected by FASD**

The FASD Support Network is pleased to advise you of a recent reprint of ***Lifeguard Strategies for Supporting Adolescents and Adults Affected by FASD***.

This booklet, created out of a workshop facilitated by Brenda Bennett, gathers the wisdom of over 40 workshop participants. Preceded by Jan Lutke's article, *Hard Issues for Parents of Adolescents and Adults with FASD: Playing Lifeguard*, the suggested strategies are presented around the themes of:

- ... Essential Beliefs
- ... Required Attitudes
- ... Successful Approaches
- ... Communication Strategies
- ... Environmental Adaptation

This booklet is packed with useful ideas that you can readily use in daily support of individuals living with FASD. It is available for download on our website or, if you prefer, contact the Network office and we will send you a free copy. Contact details on page 3.



## **Lifeguard Strategies for Working with Adolescents and Adults Affected by FASD**

### **Essential Beliefs...**

- Everyone has gifts
- FASD is a permanent disability
- Behaviour is a symptom of a disability – FASD
- IQ is not an indicator of functionality
- We can't cure or reverse the brain damage
- FASD needs to be recognized as a central nervous system dysfunction; therefore, behaviours should not be viewed as intentional



## **Better Business Bureau of Saskatchewan 2010 Torch Awards**

*The FASD Support Network of Saskatchewan has been honoured by the Better Business Bureau of SK for ethical practices in service delivery.*

Jessica Kaban, Executive Director of the Network, accepted this award and recognition for demonstrating ethics and honesty in daily practice. There are seven categories in the Torch Awards and the Network was announced as the winner for the non-profit organization category during an awards banquet on March 23, 2010.

It truly is an honour to receive this award. Acknowledgments to our funders who have provided the financial assistance needed to carry out the day to day work of our office. We would also like to thank the Better Business Bureau for this recognition. Finally, we offer congratulations to all other nominees, finalists and winners in each of the seven categories.



# Community News and Activities

## ***FASD Realities and Possibilities: The Myles Himmelreich Story - DVD***

Publishers: Saskatchewan Prevention Institute, 2009  
Reprinted with permission

Myles Himmelreich, a young man from Alberta, lives with Fetal Alcohol Spectrum Disorder. He eloquently speaks about his experiences, including both his challenges and his many successes. Myles is a seasoned presenter who has told his story to national and international audiences that include professionals, caregivers, and individuals who are themselves affected by FASD.

In this documentary Myles courageously tells his story, speaking candidly about the issues he continues to face, as well as the strategies he has used to manage and overcome them. Tom Simes, a filmmaker who is passionate about FASD education, has collaborated with Myles and the Saskatchewan Prevention Institute to create a resource that captures the engaging and informative style of Myles' presentations.

This resource includes an accompanying DVD guide, which provides discussion questions and additional information about FASD. It is appropriate for anyone wanting to understand more about FASD from an honest and personal perspective.

**For a copy of this DVD, contact Bev Drew at the Saskatchewan Prevention Institute (306) 655-2459.**

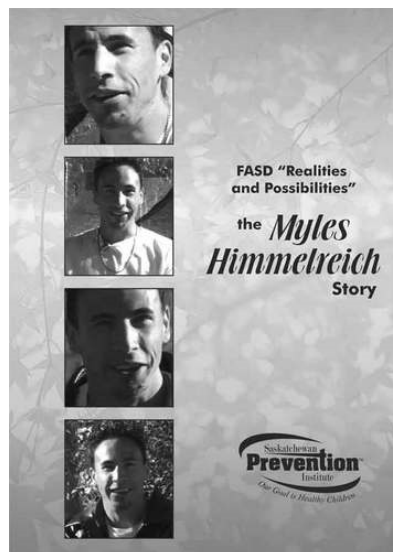
Starfish  
Award



In April, Myles Himmelreich, along with four other recipients, was presented with the Starfish Award.

This award is presented to individuals who have made significant contributions to the FASD community.

**Congratulations Myles.**



## ***Staying Connected with the FASD Community***

*FASD is an issue that is gaining greater recognition worldwide. Along with an increased awareness in specific sectors and the general public, I have also noticed a deepening of the level of understanding of the complexities of FASD.*

I expect that this increase in awareness and understanding can be attributed to the wealth of information and resources that are readily available through the various networks of the FASD community.

As always, if you are seeking information about FASD, I would suggest a visit to the Network website along with a request to be added to our contact list. When on our website, visit the **Links** section to peruse a range of valuable websites and online documents.

Remember, you can also give us a call on our toll-free line with specific requests for information. We are happy to help. See contact information on page 3.



# CUMFI Wellness Centre—

*by Eunice Bergstrom*

CUMFI Wellness Centre (CWC), March 2010

*For the past three years, CUMFI Wellness Centre has been offering mentoring services to older youth and adults who have a cognitive disability, most often FASD or suspected FASD. The intentions of this service include improved stability, safety and life satisfaction for the participants.*

Six full-time mentors are on staff, providing support according to the unique needs and goals of each individual, taking into account their strengths and interests. CWC staff builds ongoing relationships with each individual. Although there

are definite boundaries, mentors work in a flexible, interactive, non-judgmental, friendly and respectful way.

Mentoring includes vary-

ing levels of basic daily living support, such as one-on-one participation and teaching regarding nutrition, personal care and wellness, setting up daily routines, shopping, cooking, food safety, child care, housekeeping and household organization. Assistance to attain life's necessities is fundamental. This includes support in the

areas of obtaining and maintaining housing, accessing health care, income security, justice issues, employment and supported employment services and social interaction.

Mentoring encourages interaction with the local community, both socially and to access resources provided by other service providers. CWC enjoys a positive relationship with other organizations and works in conjunction with them to ensure people receive the services they require. Having a mentor allows people with cognitive disabilities to benefit or benefit more fully from other resources in the community because the mentors strive to be aware of all other resources and help with the referral and intake processes. Ongoing service is supported through assistance with making appointments and offering reminders, transportation and companionship to attend.

Also very important is the assistance provided to people to take part in positive activities through planning group activities and finding ways for individuals to build on their strengths and pursue their interests.

Although much of the mentoring takes place in the community, an important part of the CWC is a resource room that provides a welcoming place for people who are being

mentored to drop in and spend time. It may be used for practical purposes such as resume writing, filling out forms, for faxing and phoning or meeting with their mentor. Also offered there are recreational activities such as pool, fooseball, Wi games, beading, jigsaw puzzles, games and guitar playing. It serves as a place to meet before taking part in group activities or activities in the community.

The resource room is very important to the success of the CUMFI Wellness Centre in several ways. It allows mentors to be more efficient and serve a greater number of people, as it provides a meeting place (cutting down on mileage costs) and a number of people can take part in recreation at the same time at minimal cost. It is an important factor during the engagement process, as it provides a casual atmosphere and people can drop in without having to set up appointments. Parents often bring their children or may meet their children who are in foster care for supervised visits. People stop in for coffee and a visit, and come to feel part of a positive community, thus reducing the feeling of social isolation so frequently experienced by those with FASD and other cognitive disabilities.

“Creative Solutions” dollars provide a pool of flexible



# A Successful Model of Mentoring

funding that can be used creatively to meet a variety of needs. This funding can be used to obtain ID or replace lost ID that are essential for health care, education, employment, a driver's license, or banking. Funds can be used to purchase school or employment supplies, such as

a calculator and notebook, an alarm clock or winter boots.

Other examples include paying prescription fees, loonies for coin laundry, toiletries, bus tickets, a night of emergency accommodation --any reasonable cost that can make a difference in resolving an emergency,

social acceptance, and enable clients to take advantage of opportunities. Recreationally, this fund can be used to pay registrations in ongoing activities, fund group activities, purchase sports and crafts equipment that are important for mental and physical health, to combat social isolation and to build self-esteem.

Healthy newborns, children returned home from foster care and protection issues resolved, addictions treatment and sustained abstinence, improved health and health

monitoring, better housing, reduction in justice involvement and increased participation in positive activities are all signs of improved lifestyles that correlate with mentoring.

It is gratifying to see how mentoring can encourage people to maximize their strengths and abilities, and can foster stability in the lives of people who have FASD or other cognitive disabilities

For every person enrolled in the service, there are usually family members who also benefit in some way. The most obvious benefit is to their children. Although CWC is mandated to serve people of ages 15 and up, mentors are committed to strongly supporting the parenting roles of those they work with. Another obvious benefit is for family members who have been the sole supports in the past, and whose role shifts when a mentor becomes involved. Often this is a well-deserved

break from an intense supporting role. In addition, advice and assistance from a mentor is better received than it is from a parent or other close relative. In some cases, relationships with family members have reached a breaking point, so it is very reassuring to the family that mentors are now looking out for their well-being.

The only downside is that the number of people (55) that CWC is able to work with is just a portion of the number of people with FASD or other cognitive disabilities that would benefit from mentoring services in the community. A wait list is kept of new referrals with the explanation that because there is limited turnover, people on that list are likely to be waiting a long time.

For more information see the contact details below.

The resource room is very important to the success of the CUMFI Wellness Centre ...it provides a casual atmosphere and people can drop in ... reducing the feeling of social isolation...

## Contact Information

### **The CUMFI Wellness Centre**

Eunice Bergstrom, Coordinator  
315 Avenue M South  
Saskatoon, SK S7M 2K5  
Phone: (306) 975-1949



# What would a Hopeful Parent Say?

by Wendy Edey

*Every so often my son Lawrence and I have a little chat about hope. Indeed, hope has been helpful to both of us when it comes to meeting the challenges of living with FASD.*

Our hope talks generally take place in the kitchen. There we share brief snatches of wisdom while he stands at the counter, dissolving peach juice crystals

Hope is a positive feeling, a little like joy, a little like excitement. It's a feeling we have now, even though it references the future.

or arranging chicken cutlets on an oven tray. It is all part of our on-going efforts to work things out together. When I am with him I can see that there are many reasons to be hopeful. He is a handsome guy, 27 years old. He

owns a car and works in construction. When construction is slow, he works in the bike shop where he got his first high school work experience. Yet he struggles with hope, and I struggle with him. When he speaks about the future as a time when nothing good can be expected to happen, I ask myself, "What would a hopeful parent say?"

Lawrence doesn't like to talk about FASD. He says it takes away his hope. Since I would rather give hope than take it away, He and I talk more often about hope than about FASD. Yet the two subjects are

closely related.

Hope is a positive feeling, a little like joy, a little like excitement. It's a feeling we have now, even though it references the future. Hope was easy enough to find when Lawrence was little. What, after all, could possibly be more hopeful than a child? A whole life stretches ahead, love, discipline and education offer endless potential. But the dawn of adolescence brought uncertainty, the taste of fear. We began to see how the brain changes that come with FASD interfered with hope. Talking about the future became difficult. Depression and moodiness took away that hopeful feeling, and cognitive impairments got in the way when we tried to plan. I worried about how he would manage as an adult. What would he be able to do? Where could he work? He refused to discuss it.

While all this was happening, I was developing a career, counselling and teaching at a university centre for hope studies, learning the fine art of using strategies to enhance hope. Hope doesn't make disabilities disappear, but it certainly makes them easier to live with. Hope studies have conclusively demonstrated that hope helps people cope with pain, illness and stress. High levels of hope correlate with success at many things. In the course of my daily practice I would ask people to tell me where they got their hope.

Many of them would say they got it from their parents. As time went on I became more aware of wanting to be a hopeful parent, to do things a hopeful parent would do, to say things a hopeful parent would say. In order to do this, I had to think like a hopeful parent would think. Thus began a very conscious effort to search for hope in the context of living with FASD, then to find opportunities to share that hope with Lawrence.

For me, the easiest place to find positive feelings that might resemble hope was not in the

## You might also like...

FINDING  
HOPE



Ways to See Life in a Brighter Light

RONNA FAY JEVNE & JAMES E. MILLER

### Finding Hope: Ways to See Life in a Brighter Light

By Dr. Ronna F. Jevne and James E. Miller

After describing what hope is and how it works, the authors offer ideas about how to find, keep and build hope in your personal life. More than a writing about hope, this book is an experience in itself. \$10.00 (64 pages).

# What would a Hopeful Parent Say?

hope...

future, but rather in the past.

I remembered how thrilled we were the day we met Lawrence, how we played peek-a-boo around the coffee table in his foster home, how much fun it was to play with him. When I remembered this, I felt like smiling, and I found I could spread that smile to him by telling him that story. For a brief moment my gloomy teenager was that happy toddler. Moments like that could do both of us a lot of good.

As time passed, I got used to telling him stories that could help us be more hopeful in the face of an uncertain future. There were the stories about the obstacles we overcame. There had been a lot of trouble in his life at one time because he couldn't properly pronounce the letter R. Then, even though he really didn't want to pull himself away from Saturday morning cartoons, we went to see a very smart speech therapist. In only a few sessions he could say rooster better than any of the people who were teasing him. There were stories of impossible things that actually happened. One time I tried to get him moving by telling him that he wouldn't be able to get a job until he made a resume. But then, when his dad and I were at the bike shop buying his birthday present, the bike shop owner—remembering his work experience there—asked us how he was doing, asked us if we thought he would like to

work on weekends!

There were stories of the things he could do better than anybody else in the family. Climbing on the roof was one of these things. It had been a bit of a worry when he was a kid, the source of a few fights and scoldings. But now he was the one person who could take the leaves out of the eaves troughs without being scared to death.

Out of these stories came clear messages. You are strong. You are brave, you are wise. Amazing things can happen to you. He liked the stories so much that he was even willing to be in the audience at an FASD conference where I told some of his favourites. I try to remember to mention some of these memories when we stand in the kitchen, worrying about the details of an uncertain future.

These days Lawrence raises the topic of hope more often than I do. I'll be grumbling about something" maybe cursing a gadget that won't work, and he'll say, "What's all this negative talk? You're supposed to be the hope lady." From this I understand that he recognizes frustration when he sees it, and thinks of hope when we need guidance on how to deal with difficult things. "Hope," he once said to me, "is hard to find." Hard? He's right about that. At times it is hard to find. But then, hard hasn't been enough to stop us in the past.

For more from Wendy Edey, visit

**HopeLadyBlog**

[www.thehopelady.blogspot.com](http://www.thehopelady.blogspot.com)

## Contact Information

Wendy Edey is the Director of Counselling at the Hope Foundation of Alberta. You can find the Hope Foundation and all its resources in person, by telephone, email or on the web:

The Hope Foundation of Alberta  
11032 89 Avenue  
Edmonton, Alberta  
T6G 0Z6

Email: [hope@ualberta.ca](mailto:hope@ualberta.ca)  
Website: [www.ualberta.ca/HOPE/](http://www.ualberta.ca/HOPE/)  
Phone: (780) 492-1222  
Fax: (780) 492-9813

The Hope Foundation of Alberta

# International News, Research and Stories

## Faith in Fur and 4 Paws for My Son with FASD

by **Donnie Kanter Winokur**

*Okay. So maybe you have to be an "animal person". Or perhaps you have to be the kind of parent who is driven to find solutions for seemingly unsolvable challenges. Since receiving our son's diagnosis of Fetal Alcohol Syndrome, we have been humbled in ways we could never have expected.*



FASD is like the undertow...it lies in relative silence beneath the surface of the individual gathering its energy and force. Marked by co-existing disorders and peculiar characteristics, the ebb and flow of these behaviors are not exactly invisible, but can remain hidden. Some symptoms can be as gentle as a tide or swell like a tidal wave, engulfing the individual and often the caregivers or family. Living with a child affected by prenatal alcohol exposure is like living with the constant anticipation of an impending hurricane. Witnessing your child drown in a whirlpool of chemical imbalance and then resurface, keeps you hyper-vigilant for finding safe ports in the storm.

Our son, Iyal, was born in Astrakhan, Russia over 9 years ago. Iyal was adopted by my husband and me at 14 months and was diagnosed with Fetal Alcohol Syndrome about the time he became 4. In 2000, Fetal Alcohol Effects was the term given to the approximate 90% of prenatal alcohol exposed children who did not exhibit the full features of the more severe form, Fetal Alcohol Syndrome.

Because of the nature of Iyal's organic brain injury, most medications do not result in positive outcomes. In fact, they tend to make his symptoms/behaviors worse. While we have also used Physical, Occupational and Speech therapies, FASD seems to "live" outside the boundaries of these treatments...stubborn to change. Behavior Modification requires an ability to anticipate consequences for actions taken. Many people with FASDs cannot easily "learn from their mistakes". Their short term memory is limited, and unable to control impulses...they often act before they "think".

Treading water, we were always looking for new therapies, ideas...anything to help Iyal feel more in control and better about himself. Often internationally adopted children have experienced neglect or other kinds of abuse. As Iyal grew chronologically, attachment issues and post-traumatic stress responses became part of our landscape.

While I struggled with available options for support, it occurred to me that perhaps a Service Dog, SD, (also called Assistance Dogs) could be helpful to Iyal as well as the rest of our family. In truth it would "legitimize his invisible disability". Service

Animals are legally defined (ADA, 1990) and are trained to meet the disability-related needs of their handlers/clients who have disabilities. Federal laws protect the rights of individuals with disabilities to be accompanied by their service animals in public places. Service animals are not considered pets.

In the spring of 2006 I began to research everything I could get my hands on about Service Dogs (SD). I was aware of the support that Guide Dogs for the Visually Impaired and Mobility Assistance dogs could provide. I had also heard about Seizure Alert Dogs and those that were trained to help individuals with Hearing Impairments. I found several articles illustrating how SDs were now being trained to assist those with "Invisible Disabilities" like Autism, Psychiatric and Behavioral Disorders.

In all my research with interventions and treatments for FASDs I had not found a mention of Assistance Dogs trained for this specific lifelong disability. As I learned more how SD's were taught to help children with Autism...the more excited I became about the possibility of a SD learning to assist Iyal! After reading several books and researching online I submitted an application to an agency in Xenia, Ohio, called *4 Paws for Ability*. They were the first agency that began to train dogs to help children with Autism among other disorders. Within 10 months we would be blessed with a best friend for Iyal, named Chancer. Chancer was a 2 year old Pure Bred Golden Retriever who weighed 85 lbs!



Donnie with her kids

# International News, Research and Stories

## Faith in Fur and 4 Paws for My Son with FASD

How do SD's help individuals with hidden disabilities like FASD? SD's assist in several ways: they provide the child/adult challenged with this type of disability an opportunity to safely access different environments which result in improved communication and social skills. The dog's presence offers a calming influence and provides a sense of security to the child and the parents. Research shows that abstract and concrete thinking advance, focus improves, and the length of attention span increases. Emotional outbursts occur less often. The important role of the SD is affording the individual more independence and autonomy, helping them become a viable part of the community at large.



At *4 Paws for Ability* the dogs are trained case-specific. Beyond the minimum of 6 months of Public Access training, another 4 to 6 months of training occurs using video of your child. *4 Paws* provided us with a script of scenarios they wanted us to video tape. These situations included Iyal having meltdowns, tantrums, interacting with our daughter, the cats, other dogs, etc. This video then becomes the tool used to communicate to the dog what signals it will learn to assist its "human". Many children with FASDs have sensory issues causing involuntary repetitive movements. These movements thus determine the "signal" or "command" taught to the dog.

The dog is then trained to interrupt the behavior by nuzzling the child or putting a paw on the child. Many children like Iyal require Deep Pressure to calm down an over-aroused regulatory system. An 85-lb. dog could provide much needed weight to help calm Iyal when he (the dog) is lying on top of him! Up until now I have "squished" Iyal on the couch by making him the middle of a "sandwich".

Another significant concern of ours is Iyal's safety; physical and emotional. Because of Iyal's impulsivity, he often darts out into the street or a parking lot without looking. Chancer was trained to be tethered to Iyal. A dual leash attached to a belt on Iyal and to me, will afford an opportunity to keep Iyal from running out into danger. This particular skill is also used for kids who tend to wander away from their parents.

If you are familiar with the concept of "the external brain", imagine how you can apply this to a SD. We create external supports for individuals with FASDs that help them make good choices, offer companionship and provide trust and guidance. One of Iyal's external brains walks on 4 paws!

The dog's presence offers a calming influence and provides a sense of security to the child and the parents.

To add to this amazing experience we were delighted to have well-known FASD parent-advocate and published author, Jodee Kulp, join us for some of the training in Ohio. She has been breeding poodles at her facility *Knarlwoods* in Minneapolis.

Jodee, a founding Board Member for MOFAS began a pilot training program in her area. She has trained "Limey" to work with a 21-year old young man with FASD named Ken. Unbeknownst to me until just a few weeks ago...I had not heard of anyone with FASDs using a SD! Now, we not only returned with our new miracle for Iyal and our family...but Jodee and I had a chance to meet, (connect as only parents of children with FASD can) brainstorm and hopefully collaborate with our FASD efforts. To find out more about Jodee and her work visit [www.betterendings.org](http://www.betterendings.org).

Thank you for sharing in our adventure. There is so much more to tell you about the miracles these Service Dogs are bringing to families all over the world.

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### Contact Information

If you have time and interest, visit the *4 Paws* website at [www.4pawsforability.org](http://www.4pawsforability.org). You may also contact me at [dkwinkur@charter.net](mailto:dkwinkur@charter.net) or visit [www.thechancerchroicles.com](http://www.thechancerchroicles.com). Perhaps in your or your child's future there will also be a furry vehicle for healing like Chancer.

# Questions and Answers: FASD and Adoption

by Tracy Breher

Q.

*I am considering adopting a child that is suspected to have FASD. I have never talked with a parent who has adopted a child with a disability and am feeling very confused. Could tell me about some your experiences as a family and share what you have learned as an adoptive parent?*

A.

We didn't set out to adopt a child with special needs. We didn't set out to undertake a journey of learning, frustration, and at times, absolute joy. We didn't set out to challenge every idea we had about parenting or to open our minds to an entire wonderful world of determined, dedicated children with the most amazing fighting spirits. In hindsight, would we change anything? Absolutely not.

My husband and I started the adoption process early in our marriage. We optimistically signed the papers showing our acceptance of a healthy newborn baby and went home to wait... and wait... and wait.

During that time we became experts on international adoption options, and endured stages of grieving and optimism. I recall a time when I glared at everyone that I saw in public with small children. We went through the steps of a private home study and experienced heartbreak when plans for a private adoption fell apart after the baby was born. It took a little more than eight years before the letter and phone call came that started us on the home study process with the Ministry of Social Services.

During the home study, there are seemingly endless questions regarding the children you are interested in or willing to parent. We were surprised to find how broad our range of acceptance was when we started to seriously consider these questions. My brother has paraplegia; one of his best friends is legally blind. They both are wonderful people that have made significant contributions, lead fulfilling lives and have taught us so many things. They both have been able to make those contributions because of the environment and opportunities they had when they were growing up.

We added wheelchair and vision impaired to our range of acceptance. When we thought about the positive outcomes when children are provided a nurturing environment and the tools to succeed, our list of acceptance grew and grew. I have since learned that the broader your range of acceptance, the greater the likelihood of getting matched with a child. But you need to be realistic about what will work with your family and your lifestyle. Advance research is required to ensure that you are informed about the challenges you are considering.

We received the phone call about our oldest son two weeks after our home study was approved. Three weeks later he was 'home'. I will never forget what it felt like to meet him for the first time. Our second adoption was completed this past summer. It also occurred fairly quickly soon after our

home study was approved.

One son has a diagnosis, while the other is just in the process, yet both have a range of disabilities that are often associated with FASD. They have speech delays, sensory challenges, delays in processing information, and behavioural and memory challenges. And they are each absolutely remarkable in their own ways. Our oldest son was 18 months old when he joined our family. He is learning how to swim and skate, he enjoys building with Lego, likes to take things apart to see how they work and has a very admirable collection of Hot Wheels cars. Our younger son was 3 ½ when he entered our lives. He has a great sense of humour, enjoys gymnastics, builds amazing things out of play dough, and is too, determinedly growing his Hot Wheels collection.

Our sons have been impacted by factors beyond their control and beyond our control. Their prenatal history and the journey that led them to our family have shaped them in ways that require long-term, ongoing work. But those experiences have also given them admirable determination and strength of character. They both fight so hard to learn new things, and they are both doing things that they wouldn't be able to do if they didn't have such spirit. By providing them a safe environment for their personalities to develop, their skills to evolve, and for them to succeed, our boys are thriving. They teach us new things every day. They challenge us, they frustrate us, they reward us and they thrill us. There are no words



# Questions and Answers: FASD and Adoption

to define the feeling when they say "I love you Mom."

Our life is very different than what I envisioned it to be when we were first married. We have made all sorts of adaptations in our home to accommodate our sons' needs. We spend a lot of time going to appointments and advocating for services. But most importantly, we appreciate and celebrate so many things that other people often take for granted – small successes like spelling test scores or being able to sit in a

desk at school, big successes like learning how to ride a bike or functioning in a regular classroom. I am grateful to our children for teaching us to appreciate life, for making us slow down, and for allowing us to discover, every single day, miracles for which to be grateful.

We have good days and bad days. And the bad days are really bad. These days make you question your decision to adopt. At times, you want to pull your hair out in frustration. At the end of those days, we both try to find at least one "good thing" moment. Appreciating the good will enable you to move on to the next day.

It is not an easy journey to parent children with FASD. It is often isolating. In many instances, your neighbours, co-workers, and/or family won't understand what is going on with your children. People in public are often judgmental regarding your child's behavior.

And, there are limited programs available to help our children. You will learn how to fight and advocate for your child in ways that you never imagined. The lack of programs and support available is frustrating. Your child will test every parenting skill you ever thought you had.

The decision to adopt a child with FASD is yours alone. No one can make that choice for you. There are so many wonderful children waiting for their forever family. Children that have amazing skills and endless love. But those children deserve families who are knowledgeable about the journey they are about to undertake and that are able to accept and deal with the uncertainties of the future.

Is there any way to prepare to totally prepare for parenting a child with FASD? Likely not. Research is critical before you finalize your adoption range of acceptance. Talk to other parents (the FASD Support Network can connect you to parents to talk to), read about the range of possible disabilities with which you may be dealing (it is much more than limited memory recollection), and as honestly as possible, have those conversations about what your family can realistically handle.

There is a barrage of negative stories about the challenges of parenting children with FASD. They can be scary and intimidating. While they are some people's reality, I try very hard not to let the negative stories affect me. No one knows what the future holds for my family, however my sons have received

intense early intervention that we are very confident will significantly improve their opportunities as they grow older. I promised that if we were ever lucky enough to adopt one child, I would never ask for anything again. But once our oldest son reached a point where we was fairly independent and quite successful, we started talking about another child. And now that we have two, late at night when the house is quiet and everything is calm, we have started talking about just one more...



## More Information

### FASD Support Network of Saskatchewan



- ... Information about FASD
- ... Parent support
- ... Referral to community supports
- ... Become a member

### Adoption Support Centre of Saskatchewan



- 233 4th Ave S  
Saskatoon, SK S7K 1N1  
Toll-free: 1-866-869-2727
- ... For information and resources about adoption
  - ... Lending library
  - ... Become a member

Adoption News is the bimonthly magazine published by ASCS, providing our readers with the most current adoption information.





# Upcoming Events and Learning Opportunities

510 Cynthia Street  
Saskatoon, SK S7L 7K7  
Toll-Free: 1-866-673-FASN (3276)  
In Saskatoon: 975-0884  
fasdnetwork@sasktel.net  
www.skfasnetwork.ca

The vision of the FASD Support Network of Saskatchewan, a parent-led organization, is for individuals with Fetal Alcohol Spectrum Disorder and their families to recognize themselves as safe, supported, valued and contributing members of the community.

To reach this vision we provide support to people with Fetal Alcohol Spectrum Disorder, their families and circles of support by:

- ... Providing information and education
- ... Promoting early assessment, diagnosis and intervention
- ... Advocating for the development of life-long support services for individuals with FASD
- ... Establishing partnerships
- ... Working to increase awareness of FASD

## **11th FACE Research Roundtable Notice and Call for Abstracts**

Tuesday, September 14, 2010  
Plaza 500 Hotel (to be renamed "Hotel Indigo")  
Vancouver, British Columbia  
Call for Poster Abstracts—Submission Deadline: July 30, 2010  
**For questions about abstract submission please contact:  
Susan.Santiago@sickkids.ca Tel: (416) 813-8084**

## **First European Conference on FASD**

November 3 to 5, 2010  
Rolduc, Kerkrade, the Netherlands  
Call For Abstracts  
See details on the European FASD Network Website  
**[www.eufasd.org/EN/conf\\_en.php](http://www.eufasd.org/EN/conf_en.php)**

## **Online Learning about FASD**

The Government of Alberta website has a series of online presentations available for viewing. There are sessions of interest to individuals with FASD, parents, support providers and professionals from many sectors. Visit: [www.fasd-cmc.alberta.ca/home/572.cfm](http://www.fasd-cmc.alberta.ca/home/572.cfm) or search the phrase Archived Sessions FASD Learning Series.

## **Canadian Women's Health Network Website**

A great site with over 15,000 resources on women's health and gender analysis. Here is something interesting I found: Women, Mental Health and Mental Illness and Addiction in Canada: An Overview

**[www.cwhn.ca](http://www.cwhn.ca)**

## **Advance Notice: The 4th International Conference on Fetal Alcohol Spectrum Disorder**

March 2-5, 2011  
Vancouver, BC  
The Westin Bayshore  
Call for Abstracts Deadline: June 30, 2010  
**[www.interprofessional.ubc.ca](http://www.interprofessional.ubc.ca)**